

## Quest #18 June 1996

ISSN 1205-786X

### PETITIONS TO THE HOUSE OF COMMONS - UPDATE:

On Friday, May 10th, 1996 **Mrs Beryl Gaffney, MP** presented our Petitions requesting official recognition of ME/FM and Multiple Chemical Sensitivities. Mrs. Gaffney presented the Petitions for Ontario together with a speech she had prepared to the House. The following representatives presented the Petitions for other Provinces: **Mr. John Harvard (Winnipeg St. James, Lib.)**; presented the Petitions of Manitobans; **Mr. Andy Scott (Fredericton--York---Sudbury, Lib.)** presented the Petitions for New Brunswick and for Nova Scotia; **Mr. Nick Discepola (Vaudreuil, Lib.)** for Quebec; **Ms Bonnie Brown (Oakville-Milton, Lib.)** for British Columbia; **Mr. Wayne Easter (Malpeque, Lib.)** for Prince Edward Island; **Mr. John Loney (Edmonton North, Lib.)** for Alberta; and **Ms Jean Augustine (Etobicoke-Lakeshore, Lib.)** for Newfoundland.

It was like there was a multiple echo in the House when one member after the other stood up and asked the Government to ensure care, treatment, comfort and dignity for persons afflicted with these illnesses. This was in addition to Mrs Gaffney asking for official recognition. We were sitting in the Members Gallery and were joined by representatives of ME Canada; Mesh Ottawa; Compassion in Action; and Environmental Illness Society of Canada, to show that we were united in this request.

We have the **Official Report (Hansard)** for the May 10th presentation and if you would like a copy of it, please send a SSAE to us and we will be sure to forward you a copy. Please specify whether you would like this report in English or in French.

We would particularly like to thank the following people for their assistance: Leni Johnson and Bill Leeming of ME Ontario who were responsible for the wording of the Petition and its translation and in addition had made the necessary copies of it so that all we needed to do was send it out; Byron Timmermans of the Northern Ontario Fibromyalgia Association who made our path easier to travel on by constantly being in touch with members of Parliament; our former Director Mike Martin (Mr. Martin has resigned for health reasons) who had made numerous trips to Mrs Gaffney's office and to ME Canada for their support and help with Mrs Gaffney and related matters.

### DOCTORS' SUPPORT NEEDED

**The Standing Committee on Health**, of which **Mrs. Beryl Gaffney, MP** is a member, held a session with the Health Protection Branch on April 23, 1996. Dr. Lozos, Director General of the Laboratories for Disease Control (LCDC) stated that "We have mobilized two separate national consensus meetings, one on chronic fatigue syndrome and one on environmental sensitivities, at which we brought all of the experts together to try to come up with a position on what the next steps might be. On chronic fatigue syndrome, we actually also subsequently brought a group of experts together to try to come up with research proposals that they could submit to the national health research and development program of Health Canada and to the Medical Research Council to try to break the ground. That's the first step necessary to try to measure how much there is, and what it is in the population." He further stated ".....**The ball has been put directly in the court of the basic science researchers to come up with some objective measure or case definition that we in public health can then pick up to take the next publish health steps.**" [bold printing done by editor for emphasis].

[Ed. note: 1) We have written a letter to Dr. Lozos stating that we are aware of the workshop they held in February 1989 which was published in 1991 and the workshop organized by The Nightingale

Research Foundation, partially funded by Health and Welfare Canada in May 1991;

2) we again asked for official recognition etc. as well as ask them if there have been any more workshops, other than the ones mentioned above, and requesting research funds be set aside for ME/FM as well as again asking for official recognition. (if you would like a copy of our letter to the LCDC, please forward a stamped self-addressed envelope to our organization).

3) please help by contacting Dr. Joseph Lozos (copy to us) as follows: Director General LCD, Health Protection Branch, 2nd Floor, LCD Building, Health Canada, Ottawa, Ontario K1A 0L2 - Postal Locater 0602C1 - Tel. (613) 957-0315 - Fax (613) 952-8189.]

**It is now time to get the help of the ME/FM doctors.** In that regard, would you please help by sending us the name, address and phone number of the doctor(s) you are seeing so that we may be able to get in touch with them and ask for their help. Your name will not be necessary as no reference will be made to the patients who are seeing these ME/FM doctors.

**WARNING:** Much has been written about Neurally Mediated Hypotension and increasing your salt intake. Please DO NOT do anything on your own but consult your physician.

#### **UPDATE OF SUPPORT GROUPS WHO REPORTED VOLUME OF ME/FM MEMBERS:**

At present, we have received reports from 42 support groups/contacts for an approximate total of 4,470 ME/FM people. Please provide us with the name of the organization, address, phone and fax numbers, contact person and how many members are in the support group. It is important for us to get an idea on how many ME/FM people are ill in Canada. According to Dr. Lozos, they have no idea at this moment. Please rest assured that only the number of support groups and how much the total of ME/FM people are will be published and everything else will be confidential.

#### **MEDICAL PROFESSION AMENDMENT ACT, 1996 - PROVINCE OF ALBERTA - BILL 209**

The Legislative Assembly of Alberta, in its Fourth Session, 23rd Legislature, 45 Elizabeth II gave Royal Assent on May 1st as follows:

HER MAJESTY, by and with the advice and consent of the Legislative Assembly of Alberta, enacts as follows:

1 *The Medical Profession Act is amended by this Act.*

2. Section 34 is amended by adding the following after subsection (2):

**(3) A registered practioner shall not be found guilty of unbecoming conduct or be found to be incapable or unfit to practice medicine or osteopathy solely on the basis that the registered practioner employs a therapy that is non- traditional or departs from the prevailing medical practices, unless it can be demonstrated by the College that the therapy has a safety risk for that patient unreasonably greater than the prevailing treatment.**

3. *This Act comes into force on Proclamation.*

The above amends chapter M-12 of the Revised Statutes of Alberta, 1980.

1. Section 2 was further amended by striking out "by the College".

2. Section 3 is amended by adding ",but not later than October 1, 1996: after "Proclamation".

As far as we know, Alberta is the first Province to recognize alternative or complementary treatment. This Provision will come into effect no later than **October 1st., 1996.**

[Ed note: If you would like a copy of this legislation - Call Alberta Legislation General Inquiries at (403) 427-2826}

### **NATIONAL INSURANCE SURVEY - DUE DATE EXTENDED**

This questionnaire was sent out across Canada to all our members, support group leaders/contacts and the general public who had gotten in touch with us. In addition, we are grateful to all groups who had published our survey in its latest newsletters so that their members could also be part of our survey. We also thank the ME/FM people who made copies and distributed the survey. Although the due date for this Survey was June 30th, 1996 as there were still many groups who wanted to participate, we have made arrangements for surveys to be accepted by Opinion Search Inc. until **Saturday, August 31st, 1996.** If you would like to participate but don't have a copy of the survey, please let us know.

[Ed note: As of July 10th, 460 surveys have been received].

### **DISABILITY TAX CREDIT - UPDATE:**

We had written a letter to Mr. Pierre Gravelle, Q.C., the Deputy Minister of Revenue Canada regarding the unfairness of the Disability Tax Credit Form T2201 and people who suffer from ME/FM and we asked for a chance to meet and discuss it.

As a result of this, we met with Mr. K.M. Burpee, Assistant Deputy Minister and Ms Edie Pastuch, Senior Programs Officer - Processing Division on April 16th. They pointed out that it is their job to enforce the *Income Tax Act* and that they have no authority to change it. They stated that the disability tax credit "recognizes that people with severe and prolonged disabilities have higher costs of living and working. The *Act* spells out the rules for claiming the Credit. The law is intended to define as severe any mental or physical impairment that is equivalent in its effect to being blind[or deaf] or confined to a bed or a wheelchair."

He also stated that "when establishing eligibility for the credit a physician has to consider whether the patient's ability to perform the basic activities of daily living is restricted all or substantially all the time (90%), and whether the use of aids or assistive devices reduces or alleviates the restriction. Two people with the same medical condition who have different levels of functional impairment may not both qualify for the credit."

As we were about ready to leave, Mr. Burpee mentioned that in the recent budget the government announced that it would look at measures for people with disabilities and advised us whom to contact about changes to the *ACT*. We therefore sent a letter on May 27th to the Honourable Paul Martin, Minister of Finance, House of Commons, Ottawa, Ontario K1A 0A6 outlining the difficulties ME/FM people are faced with regard to this Credit and we asked for a chance to meet with him with a view of considering making changes for ME/FM people, in the same way as exceptions have been made for people who are deaf or blind.

You can help us with this by sending a letter to the Hon. Paul Martin, explaining your denial of the Tax Credit etc., and sending a copy to us so that we can further follow up.

### **AMPLIGEN UPDATE:**

**HELIX BIOPHARMA Corp.** through its news release of April 17, 1996 announced that they have formed a strategic alliance with Hemispher BioPharma Inc., to undertake the joint development of Hemispher's product Ampligen. Under the Emergency Drug Release Program, the Health Protection Branch has approved Ampligen but no details are as yet available as to costs etc. ME Canada and the National ME/FM Action Network will keep each other informed about any developments and information that may become available.

### **PROTEIN FOUND BY RESEARCHER THAT SHUTS OFF IMMUNE SYSTEM**

Dr. Luc Marengere of the Ontario Cancer Institute has identified the protein, known as SYP, that flips the switch to shut down the body's T-cells, white blood cells that kill invaders. SYP is produced within the cell on orders from a molecule on the cell surface. The switch molecule, CTLA-4, acts as the general, ordering the proteins to do the physical work of halting activity in the cell so it will stand down when the immune defence is complete. Dr. Marengere stated that "Since the immune system is at the heart of things like cancers, AIDS, infections and autoimmune diseases, these finding give us knowledge to begin to explore treatments in a range of diseases." He further stated that a breakdown in the chain of command allows the immune cells to remain on the attack, eventually striking friendly cells. Attack by uncontrolled T-cells is believed to be behind many autoimmune diseases.

[Source: *Ottawa Citizen*, Saturday, May 25, 1996, page A12]

### **NATIONAL LIFE (NL) ADMONISHED BY JUDGE**

A 50 year old, disabled OC [Ottawa Carleton] bus driver, Jim Ferguson, suffers from agoraphobia, a morbid fear of public places or the outdoors. He was paid a disability income by NL for two years and then offered him a six months payment in a lump sum to sign off his claim. Upon the advice of his doctors he refused. NL continued to pay but then using assessments from its experts, it cut off benefits and closed the file which in turn caused his employer to remove him from the company pension plan, forcing him to hire a lawyer. It took 6 years to work the case up the court system to trial and then 19 days of trial. Justice Judith Bell found wrong with NL's methods and its choice of experts. Its two main witnesses were a man identified as an accredited rehabilitation worker and a Montreal psychologist. The former was accredited by himself and the latter was 70 and retired. NL used these two to override the reports of physicians and psychiatrist. Judge Bell observed that the rehab worker '...could not even define the type of job function the plaintiff could perform... and took no proactive role in any job search.' The judge was even harsher on the retired Montreal psychologist who used the word 'malingerer' in his report to the insurer. "I would attach no weight to his opinion' said the Judge. She said the witness was 'biased' in support of the insurer and that was most evident in his stated view that the plaintiff was well enough to drive a school bus. Judge Bell said that the insurer's actions deserved punishment and awarded punitive damages of \$7,500 plus what the Fergusons thought was an award of \$150,000. Unfortunately NL appealed the decision. NL's in-house lawyer, James Newland, said that the Fergusons are in a no-win situation as any settlement they get 'will be eaten up' by legal costs and repayment to welfare. There also is a \$30,000 lien on their home.

[Ed note: From the people who have contacted us, it seems to be the standard that the first two years are paid readily enough by an insurer but after that the claimant is put into a position to get a lawyer and sue the insurer. When it is almost time to go to trial, on the last moment, the insurer then offers a bulk settlement complete with a gag order. As a result of this, it is impossible to find out whether the settlement was fair or not. Hopefully, our insurance survey will give us some answers.]

## **TREATMENT OF GULF WAR ILLNESS (GWI) OF USE FOR SOME ME/FM PEOPLE?**

In his reply to our organization, **Professor Garth L. Nicolson, of The University of Texas M.D. Anderson Cancer Center** stated that they have found that about 50% of the GWI[Gulf War Illness]-CFIDS patients have an invasive mycoplasma infection that can be successfully treated with antibiotics, such as doxycycline or Cipro. He has found that a large subset of CFIDS patients respond quite well to doxycycline. Dr. Nicolson said that "If they [CFIDS patients] have a sympathetic physician, their physician should consider trying a 6 week course of 200 mg/day doxycycline. We have found that a large subset of CFIDS patients respond quite well to doxycycline, but the treatment takes some time, similar to Lyme Disease. Several CFIDS patients here in Houston responded well and recovered after a few 6-week cycles of antibiotic. Alternative antibiotics are Cipro (1,000 mg/day) and Zithromax (500 mg/day)."

{Ed note: 1) Professor Nicolson asked that if anyone tries this treatment, would they please advise him if it has alleviated any of the CFIDS systems;

2) To obtain a copy of Dr. Nicolson's letter to us, please send us a stamped self-addressed envelope.}

3) Please send us a copy of your letter to Dr. Nicolson. (Your name will be kept confidential).

## **ADDITIONS TO DOCTORS' ROSTER**

**\*DAVID BAYLEY, Bsc., N.D.**

**#100 - 3711 Delbrook Ave. Tel. (604) 986-9191**

**North Vancouver, B.C. V7N 3Z4 Fax (604) 986-9145**

**\*Dr. Bayley also lectures on Diagnosis and treatment of ME/FM options to support groups and health-care professionals.**

**\*JOHN G. THOMSON, M.D. Rheumatology**

**340 McLeod St., Suite 205**

**Ottawa, ON K2P 1A4 Tel. (613) 232-2604**

**\*Dr. Thomson diagnoses and treats for Fibromyalgia Referral needed from licensed physician.**

**\*GARY ADAMS, Chiropractor**

**The Durham Chiropractic and Rehabilitation Centre**

**420 Cawforth St.**

**Whitby, ON L1N 3R5 Tel. (905) 430-0830 Fax (905) 430-0153**

**\*The Center provides treatment for ME/FM patients, active treatment programs for individuals who have been injured in motor vehicle accidents and the rehabilitation programs include assessment, physical therapy and patient education. Rehabilitation and chiropractic care are two distinct and**

separate services so that it allows patients who have their own chiropractor or physician to attend the Centre for rehab services only.

#### **ADDITION TO LAWYERS' ROSTER**

**\*MR. BRAD D.S. GARSIDE s:\wp\home\bgarside\corres\mefm.L01**

**PAINE EDMONDS**

**Barristers & Solicitors**

**Montreal Trust Centre**

**510 Burrard St., Suite 1100 Tel. (604) 683-1211**

**Vancouver, British Columbia Fax (604) 681-5084**

**V6C 3A8**

**\*Mr. Garside takes referrals from existing clients as well as the Fibromyalgia and M.E. support organizations in the Greater Vancouver area of British Columbia. He will take cases on private disability insurance, personal injury and arising from motor vehicle accidents.**

[Ed note: Mr. Garside has also forwarded a copy to all his ME/FM clients of our National Insurance Survey for which we thank him].

**\*MR. ERIC HERINGA**

**PAINE EDMONDS**

**Barristers & Solicitors**

**Montreal Trust Centre**

**Ellwood Centre**

**202 - 31205 Old Yale Road**

**Abbotsford, British Columbia Tel. (604) 864-8445**

**V2T 5E5 Fax (604) 864-8445**

**\*will see clients in the Abbotsford/Fraser Valley area (including the cities of Abbotsford, Langley, Mission and Chilliwack).**

#### **INTER-GROUP/CONTACT COMMUNICATION**

**The Medical Professionals/Persons with CFIDS (MPWC's)** is a support group for people who worked in any medical field prior to developing ME/FM i.e. physicians, nurses, medical technologists, pharmacists etc. or any other profession which involved exposure to patients and/or blood/fluid/tissue specimens of patients. MPWC's feel that it is vitally important that these

professionals all unite so that their voices can be heard. Please write to **LORI CLOVIS, M.A., P.O. BOX 144, HINSDALE, NY 14743 U.S.A.** if you are interested in joining this Group.

**Congratulations to The New Brunswick ME/CFS Association** who held their first "The Elephant Walk" annual fundraiser for ME/CFS. The "Elephant" is the mascot for the Association because it represents the weight of illness on those who suffer with ME/CFS. The walk resulted in them raising \$2,300 with an additional \$1,300 or so in pledges and donations. With these funds they were able to have a toll-free number and business line installed (Toll free number for New Brunswick only), purchase a fax machine and a photocopier for their office.

If you would like information on how to host an "Elephant Walk" as a possible fundraiser for your group, please call or write: Ms Brenda Duffy, President, NB ME Association, 15 Rosewood Drive, Fredericton, NB E3B 7G8 - Tell (506) 452-9739.

### **BOOKS / NEWSLETTERS / REPORTS / VIDEOS ETC.**

**WHY WE BECOME ILL (2 pages) or POURQUOI DEVONS-NOUS MALADE (3 pages): by Dr. Philipa Corning.** Please send stamped self-addressed envelope, if you would like a copy of this report, and send your request to Dr. Corning, 69 Roblyn Way, Nepean, ON K2G 5Z5, Canada.

**1) Fibromyalgia, Managing the Pain - \$12.45 U.S.; 2) The Fibromyalgia Survivor 19.50 U.S.; 3) Laugh at your Muscles - \$5.95 - by \*Mark J. Pellegrino, M.D. Publisher: Anadem Publishing Inc., 3620 North High Street, Columbia, Ohio 43214 USA - Tel. 1-800-633-0055 or (614) 262-2539 - Fax (614) 262-6630 E-Mail: anadem@coil.com.**

There is a discount of \$3.50 if you order all three books. Discount on volume also available.

[Ed note: Dr. Pellegrino has had FMS since he was a child. His philosophy in treating fibromyalgia is "to find whatever works and learn a responsible, successful home program."]

**TMJ - Its Many Faces by Wesley E. Shankland, II D.D.S., M.S. \$19.50 U.S. plus \$3.50 S & H.** Advice on managing and resolving pain related to the temporomandibular joint (TMJ), including all types of head and facial pain. {Publisher: Anadem Publishing Inc. - same details as above regarding ordering.

**ME The New Plague by: Jane Colby. Price: 12.95 Sterling plus 3.50 sterling S & H. Publisher: First and Best in Education Ltd., 34 Nene Valley business Park, Oundle, Peterborough, PE8 4HL England - Tel. 01832 275285 or Fax 01832 275281.**

[Ed note: Ms Colby is a former teacher and suffers from ME herself]

**BETRAYAL BY THE BRAIN - The Neurologic Basis of Chronic Fatigue Syndrome, Fibromyalgia Syndrome, and Related Neural Network Disorders: by J.A. Goldstein, MD.** \$49.95 U.S. each (hardcover) and \$29.95 U.S. softcover. Publisher: The Haworth Press, 10 Alice Street, Binghamton, New York 13904-1580 U.S.A. Toll free by phone: 1-800-342-9678; by fax 1-800-895-0582; and by E-Mail: [getinfo@haworth.com](mailto:getinfo@haworth.com).

### **OUR WORLD**

ME/FM: The 'now what' illness: Everytime that you think that you are used to all its symptoms, a new one crops up and you find yourself saying 'now what!'.

Accept your illness but refuse to become a victim of it.

**MEMBERSHIP: \$20.00 per year which includes newsletters every two months. Please show your support by becoming a member and joining the Action.**

**ELECTRONIC MAIL: our e-mail address: [ag922@freenet.carleton.ca](mailto:ag922@freenet.carleton.ca)**

**A free Guide** to the many information resources available via Computer for chronic Fatigue syndrome/Myalgic Encephalomyelitis and Fibromyalgia. For an individual the guide shows where to get information and have discussions with others interested in ME/CFS and FM. For a Support Group, the guide is a resource for obtaining newsletter articles for your newsletters, and to communicate with other support groups. You can obtain a free copy by mailing a self-addressed stamped envelope to:

In Canada: CFS/ME Computer Networking Project, 3332 McCarthy Road, P.O. Box 37045, Ottawa, Ontario K1V 0W0, Canada.

In the United States: CFS/ME Computer Networking Project, P.O. Box 11347, Washington, DC 20008-0547 U.S.A. Please note that for mailing outside of Canada please include an International Reply Coupon.

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